"Shoot for the moon; the worst that can happen is that you end up somewhere in the stars."

Bill Demby

This Alert is a vehicle of communication between the Alliance and the genetics community. It is our goal to provide timely and useful material in readable, easy access format. Feel free to send in your announcements, share your ideas, or ask for help.

IN MEMORY OF AN ALLIANCE FRIEND
On behalf of staff, board and members, the Alliance extends condolences to family members and close friends on the recent death of Beth Fine, M.S. The genetic counseling and consumer communities lost a generous and dedicated friend who we will remember for her warmth, attentiveness, spirit and courage.

MEMBERSHIP CONFERENCE ALERT
Art of Reporting Award: This award will be presented to a reporter with a proven track record for sensitivity, accuracy and understanding of consumer issues on Saturday, September 12, 1998 at the Alliance Membership Meeting. Send us the name of your favorite reporter along with documentation of the reporter's work.

Art of Listening Award, "Hearing is a Gift, Listening is an Art": This award is presented to professionals whose daily work, despite the busy pace of clinical practice, demonstrates the highest commitment to listening and understanding the individuals and families that seek their counsel. The Alliance underscores the importance of professional compassion, patience and attentiveness as invaluable components of quality care. To nominate someone who you feel meets these qualifications, write a letter to Alliance Board member Jayne Mackta, c/o the Alliance, explaining why this person should be recognized. The Art of Listening Award will be presented at the September 1998 Alliance Membership Meeting; travel and lodging expenses for the winner and the nominator will be funded through a grant from the Morris J. and Betty Kaplun Foundation.

FORGING GENETIC PARTNERSHIPS: RESEARCHERS, POLICY MAKERS AND CONSUMERS
Speakers: Alice Wexler, Ph.D., Francis Collins, M.D., Ph.D. and Paul Miller, J.D.
Participants: Consumers, Support Group Leaders and Professionals
Topics: "Using Your Personal Story to Frame Policy Issues"

Save the date and call for more information Mary Ann Wilson 202-966-5557, ext 206

PUBLIC POLICY & LEGISLATION
Human Genome Project Five-Year Planning Meeting: Scientists and public representatives met on May 28 and 29 to evaluate, debate and approve the next Five-Year Plan for the Human Genome Project's scientific and Ethical, Legal and Social Implications (ELSI) research programs. Alliance executive director Mary Davidson and other lay persons represented consumer interests and concerns in discussions that defined the goals and objectives of the ELSI Research Program. There was considerable discussion of issues raised by the recent announcement by The Institute for Genomic Research in Rockville, MD and the Perkin-Elmer Corporation merger that their private sector sequencing efforts, which involve a different process, would be complete by 2002. There was clear evidence of the HGP research community's determination to maintain current quality standards while speeding up sequencing efforts and addressing ELSI issues.

Electronic Communication about Legislative Alerts: We are setting up an e-mail system to send out legislative alerts and want to confirm your current e-mail addresses. This will enable us to get the word out to you about interesting and urgent hearings, letter writing campaigns, petitions and other legislative educational activities. If you want to participate, please send your e-mail address and the name of your organization to info@geneticalliance.org, with a subject heading of "legislative link."

The Alliance ALERT is a publication of the Alliance of Genetic Support Groups, 4301 Connecticut Avenue, Suite 404, Washington DC 20008 • 1-800-336-GENE • 202-966-5557 • e-mail: info@geneticalliance.org • fax: 202-966-8553 • website address: http://www.geneticalliance.org • The ALERT is funded in part by Project #2MCJ-241009-06-0 from the Genetics Services Division of the Maternal and Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services and the Community Partnership Program of SmithKline Beecham, Inc.
"Integrating Genetic Advances into Public Health": From May 13 to 15 the CDC hosted more than 400 genetics and public health professionals from Maternal and Child Health Bureau, the National Human Genome Research Institute and the Public Health Service at the first annual Genetics and Public Health conference. As the single voice for consumers, the Alliance was represented by Jannine Cody, Ph.D., Mary Davidson and Joan Weiss.

The Consumer Voice: An enhanced consumer presence within the national policy dialogue is urgently needed. Policy discussions will benefit from the experience and contributions of those with first-hand experience and who will be most impacted by those decisions. Please contact Mary Davidson at 202-966-5557, ext. 207, if you have particular interest and expertise in the following topics: public health, newborn screening, gene patenting, clinical research participation, insurance underwriting, IRBs and medical records privacy.

Senate Hearing on Genetic Discrimination: The Committee on Labor and Human Resources met on May 21 to hear public testimony on the treatment and privacy of genetic information and medical records. A packed audience listened to presentations by Senators Snowe and Domenici, Dr. Francis Collins, representatives from The National Breast Cancer Coalition, Hadassah, the National Society of Genetic Counselors and the health insurance industry. Consumer, professional and research concerns prompted serious and thoughtful questions from committee chairs Senators Jeffords and Kennedy and other Committee members. Written testimony was submitted by the Alliance and can be requested from Mildred Stewart at 202-966-5557, ext. 201. To prepare for future hearings, we need to hear from members about incidents of genetic discrimination. Please contact Holly Landrum, at 202-966-5557, ext. 211.

Birth Defects Prevention Act of 1998: On April 22, President Clinton signed into law the Birth Defects Prevention Act of 1998, a $70 million initiative to research and collect information on birth defects. Currently, the United States does not have a reliable regional or nationwide system for collecting information on infants born with birth defects. This initiative will provide funding for surveillance, research and services with the goal of preventing birth defects. March of Dimes Birth Defects Foundation representatives joined the President for the formal signing of the bill.

ALLIANCE NEWS

Graduate Genetic Counseling Program Acceptances: The month of May was the bearer of good news for three Alliance interns and volunteers who received the following invitations to genetic counseling graduate programs. Nancy Hsu will attend University of Wisconsin at Madison, Kara Gardner will attend Sarah Lawrence College and Edie Lebson will attend University of Maryland at Baltimore. We are thrilled that you are starting off your genetic counseling careers in close contact with consumer issues. Congratulations to all three of you!

Please Send Nominations: The Board of Directors’ election are coming up in the fall by mail ballot. We are looking for new energy, talent and interest. Please send your suggestions for consumer and professional board members to Betsy Trombino, chair of the nominations committee at jbtrom@aol.com.

Welcome to New Alliance Staff! Mildred Stewart joined the Alliance family on May 6, 1998 as Research Administrative Assistant. Her time will be split between the Partnership Program and general Alliance activities.

HuGEM II Update: Educational meetings are being held on ethical and psychosocial issues related to genetic testing and research. One meeting recently took place at a National Women’s Democratic Club seminar; another at the national American Orthopsychiatric Association conference. Consumers Mary Beth Busby from FRAXA and Larry Allen with the Virginia Sickle Cell Association made major contributions at these meetings. The HuGEM II survey is now being tested with a small sampling from each of the 7 targeted allied health professional organizations.


Partnership Update: The Partnership Program is pleased to report that responses to the blue Consumer Guideline surveys in the March Alert continue to trickle in. We are only 5 responses away from receiving our goal of 100. Managed Care Project: Program staff have completed initial interviews with department heads of NYLCare Corporate in efforts to refine evaluative tools. !HELP! — We need a sample of your resources to review and catalog for appropriate integration into our managed care pilot sites. They are to be used by the Genetic Service Teams (GST) — charged with the assessment and intervention phases of the program’s work within pilot sites. Please send them ASAP — to the attention of Mildred Stewart. Medical School Project: The project is well underway thanks to efforts with GLaRGG. Program staff intend to use the summer break to develop new contacts, a program package, and to refine the training curriculum for our next Consumer Educator orientation in November ’98. Anyone living in the Great Lakes region and interested in participating in the November orientation should contact Bowie Little at the Alliance at 202-966-5557, ext. 203.
USEFUL RESOURCES: The Complete Directory for People with Chronic Illness: The Alliance has recently acquired The Complete Directory for People with Chronic Illness as a new resource to supplement current resources used for referral on our toll-free helpline. This directory, published by Grey House Publishing, provides listings of resources for chronic conditions, including many genetic conditions. Resource listings include support groups and hot lines; research centers; national agencies; state agencies; and published books, magazines, videos, newsletters and pamphlets. For more information about this directory, contact Holly Landrum at (202) 966-5557, ext. 211.

GETTING TO KNOW THE COUNCIL OF REGIONAL NETWORKS FOR GENETIC SERVICES (CORN)

In coming months, the Alliance will introduce the ten regional genetics networks, which are an integral part of the Council of Regional Networks (http://www.cc.emory.edu/PEDIATRICS/corn/corn.htm). Each regional network offers unique and valuable resources to consumers, professionals and the public. This month we introduce to you another network — the Mountain States Regional Genetic Services Network (MSRGSN) (http://ahsc.arizona.edu/msrgsn/). Funding for CORN is provided by the Genetic Services Branch of the Maternal and Child Health Bureau.

The MSRGSN was established in 1984 and is funded by a grant (#MCJ-081002-02) from the U.S. Department of Health and Human Services, Division of Maternal and Child Health, Genetic Diseases Services Branch.

The MSRGSN is made up of genetic service providers and consumers from six Rocky Mountain States: Arizona, Colorado, Montana, New Mexico, Utah, and Wyoming. Over two hundred members include physicians, geneticists, cytogeneticists, molecular biologists, genetic counselors, genetic nurses, public health officials and persons affected by genetic conditions and their families. MSRGSN emphasizes consumer participation in their region and through the active participation of both public and private genetic service providers.

The MSRGSN mission is divided into nine principle goals:

• to assess the need for genetics services throughout the region
• to establish and maintain a database of genetic services provided in the region
• to promote collaboration and the sharing of resources among genetics professionals throughout the region
• to promote cultural sensitivity and consumer participation in genetics service issues
• to develop and carry out genetics education for primary care and other health care providers
• to assist member states with integrating genetics services into their maternal and child health programs
• to monitor the quality of clinical and laboratory genetics services within the region
• to collaborate with the Council of Regional Networks in addressing public health genetics issues at the state and national levels
• to measure the impact of managed care on genetics services within the region and to act to assure comprehensive genetics service access to all

MSRGSN Committees
- Clinical Services Committee
- Consumer Issues Committee
- Cytogenetics Committee
- Education Committee
- Molecular Genetics Committee
- Newborn Screening Committee
- Prenatal Diagnosis Committee
- Data Committee
- Finance Committee

MSRGSN Publications & Resources
- MSRGSN Region Genetic Services Directory
- Newborn Screening Practitioner’s Manual (available in Spanish)
- Questions You May Have for Your Genetic Specialist (available in Spanish)
- Thinking About Pregnancy — A Preconception Brochure (available in Spanish)
- Triple Marker Screen (available in Spanish)
- Genetic Drift — Biannual Resource Documents
- Lending Library — Videos, Slides, Cassettes and Books

For more information about MSRGSN, contact:
Joyce Hooker, Coordinator, MSRGSN
Medical Affairs & Special Programs
4300 Cherry Creek Drive South
Denver, CO 80246-1530
joyce.hooker@state.co.us.

UPCOMING MEETINGS AND ANNOUNCEMENTS: Member groups wishing to submit a meeting or conference announcement to the Alert are asked to provide information in the following format: conference name, date, location, contact information, name of organization, mailing address, telephone number and e-mail address.


Annual Cystinosis Fdn Conference • July 2-4. Ann Arbor, MI. Contact Jean Hobbs Hotz at 1-800-392-8458.

19th Annual Intl Conference of the Cornelia de Lange Syndrome Foundation, “Thousands of Lakes, Millions of Dreams” • July 2-5. Minneapolis Hilton & Towers, Minneapolis, MN. Contact Gretchen Vakiener, 1-800-753-CDLS.

14th Annual National Marfan Foundation Conference • July 8-12. New York Hospital/Cornell Medical Center and the Roosevelt Hotel in New York City. Contact NMF at 1-800-8-MARFAN.


Aicardi Syndrome Family Conference • July 17-19. Holiday Inn Conference Center, Fairborn, OH. Contact Denise Park at 937-368-2137.

20th Annual Prader-Willi Syndrome Association • July 22-25. Columbus, OH. Contact PWSA at 1-800-926-4797

4th Annual MAGIC Foundation Conventions • July 23-26. Chicago Marriott Oak Brook Hotel, Oak Brook, IL. Contact MAGIC at 1-800-3-MAGIC-3.

Late Onset Tay-Sachs Foundation Annual Conference • July 23-25. Wyndam Franklin Plaza Hotel, Philadelphia, PA. Contact Bobbi Fishbein at 1-800-672-2022.

Alzheimer’s Association 7th National Alzheimer’s Disease Education Conference • July 26-29. Indianapolis Convention Center, Indianapolis, IN. Contact Michael Pirages at 312-335-5764.

National Association of Pseudoxanthum Elasticum • July 31-August 2. Denver, CO. Call NAPE at 303-355-3866.


Families of Spinal Muscular Atrophy Annual Family & Professional Conference • July 31-August 2. Hyatt Regency Technology Center, Denver, CO. Contact Families of SMA at 1-800-886-1762.

Alliance Board of Directors: Joan Burns, M.S., President; Jayne MacKta, Past President; Leslie A. Platt, Esq., Treasurer; Peggy Mann Rinehart, Vice President for Consumers; Ann C.M. Smith, M.A., Vice-President for Professionals; Jannine Cody, Ph.D.; Brad Margus, M.B.A.; Theresa Hadley, M.S.W.; Betsy Trombino; Debra Collins, M.S.; Susanne B. Emmerich; Nelson Freed.

Alliance Medical Advisor: Reed E. Pyeritz, M.D., Ph.D. Alliance Executive Director: Mary E. Davidson, M.S.W.